The effect of care-recipient behavioral and psychological symptoms of dementia and mood on caregiver stress

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Abstract

Alzheimer's disease is a chronic illness that significantly affects cognitive function, and cannot be cured. Caregivers of those with Alzheimer's disease face significant amounts of stress related to caregiving. While some research exists to explore the relationship between cognitive function of the care-recipient and stress of the caregiver, there is a gap concerning the relationships between care-recipient moods, care-recipient behavioral and psychological symptoms of dementia (BPSD), and caregiver stress. The purpose of this secondary analysis was to explore these relationships, guided by the Roy Adaptation Model of Nursing. In this study, 47 caregivers completed two assessments: the Alzheimer's Disease Mood Scale (AMS) and the Neuropsychiatric Inventory Questionnaire (NPI-Q). AMS addresses care-recipient moods, while NPI-Q addresses care-recipient behaviors and the resultant caregiver stress. Univariate correlations and multivariate regressions were used for analyses. The results of this study indicate that care-recipient hostility (ρ=.35, $p \leq 0.05$), sadness (ρ=.54, $p \leq 0.05$), contentment (ρ=-.43, $p \leq 0.05$), BPSD prevalence (r=.78, $p \leq 0.05$) and BPSD severity (r=.84, $p \leq 0.05$) are related to caregiver stress. Additionally, certain care-recipient moods have significant relationships with BPSD prevalence (hostility: r= 0.54, $p<0.0001$) and BPSD severity (sadness: r=0.48, p= 0.008; contentment: r= -0.58, $p< 0.001$). Further research is needed to better analyze the individual effects of care-recipient moods and BPSD on caregiver stress, as the variables are closely related and require more thorough assessment.

Introduction

Of the top ten causes of death in the United States of America, Alzheimer's disease is the only one that currently cannot be prevented, cured or slowed (Alzheimer's Association, 2015). The majority of care for persons with Alzheimer's disease falls on informal caregivers, namely unpaid family members. Caregiving exerts heavy tolls on family caregivers, with almost 60% describing the emotional stress of caregiving as high or very high (Alzheimer's Association, 2015). In addition to the average $5000 a year that family caregivers spend caring for someone with Alzheimer's disease, caregivers experience new diseases or worsening of existing conditions due to caregiving, which amounted to another $9.7 billion in health care costs (Alzheimer's Association, 2015).

Caregiver stress is a phenomenon involving multiple facets including caregiver self-efficacy (Gallagher, 2011; Nogales-González, 2015), coping skills (Garlo, 2010) and personality aspects (Löckenhoff, 2011). The increased severity of Alzheimer's disease appears to directly correlate with increased levels of caregiver stress (Kamiya, 2014). Generally, it is believed that as the cognitive decline of Alzheimer's disease worsens, the patient's BPSD increase (Kamiya, 2014). Previous research indicates that the presence of BPSD is a large contributor to caregiver depression (Matsumoto et al., 2007). Approximately 40% of caregivers of family members with Alzheimer's disease suffer from depression (Alzheimer's Association, 2015). However, there is a lack of knowledge on the effect of care-recipient moods on the levels of caregiver stress. If the relationships between care-recipient BPSD, mood and caregiver stress are better understood, there is potential to reduce emotional stress in caregivers by developing new interventions.

Research Purpose Statement

The purpose of this study is to examine the relationships between care-recipient mood, BPSD and caregiver stress in Alzheimer's disease.

Research Aims

The aims of this study are:

1. Examine the relationship between care-recipient mood and caregiver stress.
2. Examine the relationship between BPSD exhibited by persons with Alzheimer's disease and caregiver stress.
3. Examine the relationship between BPSD and mood of the care-recipient.

Significance for Nursing

As the rate of Alzheimer's disease continues to climb, nurses are seeing an increasing number of patients and caregivers struggling to cope. Nurses need to take care of the caregiver in addition to the care-recipient with Alzheimer's disease. By understanding how the mood and BPSD of the care-recipient may affect caregiver stress, nurses have an opportunity to cultivate comprehensive, evidence-based interventions to improve care-recipient mood and mitigate BPSD. The improvement of mood and BPSD benefits the individual with Alzheimer's disease in addition to the caregiver, and reduces overall mental and physical health costs.

Literature Review

Key searches were conducted using Ovid Medline. Individual searches were conducted using search terms of interest, including "Alzheimer's disease", "caregivers", "stress", "affect", "emotions", "BPSD", "depression", "self-efficacy", "coping" and "adaptation." The terms "Alzheimer's disease", "caregivers" and "stress" were of particular interest, and were therefore set to include associated subheadings and focused to guarantee the keyword was one of the

primary keywords in the articles. The following inclusion and exclusion criteria were used to refine the literature searches. Inclusion criteria included written in English, published since 2000 and published in a peer-reviewed journal. Exclusion criteria included articles inaccessible through the University of Minnesota Libraries, and articles that did not focus on Alzheimer's disease or caregiving. Secondary information was gathered from the Alzheimer's Association of America's website. The literature review focused on four key areas: mood in Alzheimer's disease, behavioral and psychological symptoms of dementia in Alzheimer's disease, the nature and impact of caregiver stress in Alzheimer's disease, impact of Alzheimer's disease on the caregiver, and contributing factors to caregiver burden and stress.

Mood in Alzheimer's Disease

An estimated 20-51% of patients with Alzheimer's disease present with mood dysregulation, most often depressive symptoms (Votruba, 2015). The detrimental effect of Alzheimer's disease on mood was also highlighted by Bayard, Jacus, Raffard, and Gely-Nargeot (2014), with 60% of the Alzheimer's participants experiencing slight to severe apathy, a known depressive symptom, compared to just 5% of healthy controls. Furthermore, as the severity of depressive symptoms in the care-recipient increases, the performance of their activities of daily living (ADLs), such as eating, bathing, dressing, toileting and transferring decreases (Votruba, 2015). These findings suggest that the mood of the person with Alzheimer's disease can negatively impact their quality of life.

BPSD in Alzheimer's disease

BPSD include apathy, irritability, wandering, elation, depression, anxiety, sleep problems, agitation, misidentification, confabulation, feelings of persecution, and hallucinations. According to the Alzheimer's Association (2016), BPSD "describe a large group of… symptoms

that occur to some degree in many, but by no means all, individuals with Alzheimer's." In essence, not all care-recipients with Alzheimer's disease experience the same BPSD with the same severity. Savva (2009) finds that dementia patients experience all of the aforementioned symptoms, except confabulation and sleep problems, at significantly higher rates than people without dementia. Wandering is substantially more common in those with dementia.

Impact of Alzheimer's Disease on the Caregiver

Physical demands, the emotional stress related to Alzheimer's disease behavior, relationship changes, fatigue, and depressive symptoms are especially challenging for caregivers (Angelo, 2014). The act of caregiving tends to become the most dominant component of a caregiver's emotional existence as well (Potgieter et al 2011). It is purported that although helping valued loved ones may promote personal wellbeing, the transition to a caregiving role is often marked by a loss of reciprocity between partners, which makes the act of helping feel more taxing (Poulin, 2010). Not surprisingly, fatigue is significantly higher in caregivers compared to non-caregivers (Roepke, 2009). Compared to non-caregivers, caregivers of those with Alzheimer's disease are about eight times more likely to report depressive symptoms and to meet clinical cutoffs for depression (Mausbach, 2012). The same study reported that of the 25% of caregivers taking an antidepressant medication, 69% continued to experience significant symptoms of depression.

In an earlier study by Matsumoto et al (2007), delusional thoughts, agitation, apathy, irritability or aberrant motor behaviors displayed by a loved one with Alzheimer's disease were related to higher levels of caregiver stress. Furthermore, the burden on caregivers associated with BPSD is different for each symptom and does not necessarily depend on frequency or severity (Matsumoto, 2007). A separate study suggests similar findings, in which BPSD impact varies by

the extent that the caregivers perceive them as unpredictable, uncontrollable and/or distressing (Nogales-Gonzalez, 2015). Of note, verbal aggressiveness and apathy appear to cause higher levels of caregiver stress than other types of BPSD (Kamiya, 2014). Overall, the impact of Alzheimer's disease on caregiver health is extensive.

Contributing Factors to Caregiver Burden and Stress

Overall, the relationship between care-recipient mood and caregiver stress is still relatively unexplored. There is a diverse response to caregiving demands; some caregivers are overwhelmed with their care-recipient's condition, while others emotionally stabilize or even improve over time (Gallagher, 2011). High caregiver burden, however, is thought to be the strongest predictor for poor quality of life of the caregiver (Abdollahpour, 2014). Burden also appears to be higher for caregivers who care for those with lower global functioning (Kamiya, 2014). Regarding care-recipient mood and caregiver stress, only two studies, written by Izawa (2010) and McGilton (2011) substantially addressed these issues. Izawa (2010) found that caregivers' depressive symptoms are associated with the depressive mood of care-recipients. McGilton (2011) found that the positive mood of residents in long-term care settings was associated with more effective caregiving abilities as demonstrated by the facility employees.

This project aims to fill the knowledge gap of the effect of care-recipient mood on caregiver stress by examining the relationships listed in the "Research Aims" section. A short term goal is to better understand these relationships and search for significance. A long term goal is to expand upon the findings of this thesis and corroborate with previous findings of other research so that new interventions may be developed to mitigate Alzheimer's mood dysregulation, BPSD, and caregiver stress.

Conceptual Framework

This project will be guided by the Adaptation Model of Nursing (Figure 1), developed by Sister Callista Roy (1976). In her model, humans aim to adapt to situations by continuously interacting with their environment. At the core of this model, there are three coping processes, which influence behavior:

- Integrated Coping, in which effective and stable coping methods are in place so that human needs are met.
- Compensatory Coping, a time of growth and transition as coping mechanisms are activated by a challenge such as Alzheimer's disease. If this coping process is not successful, it can lead to Compromised Coping.
- Compromised Coping, in which ineffective coping methods such as lashing out at loved ones, withdrawing or turning to harmful substances, are manifest due to problems in the adaptation process.

Accordingly, nurses can use the Adaptation Model of Nursing to help caregivers adapt to stressful situations successfully. This goal can be achieved by exploring why certain stimuli compromise the coping process, then helping the caregivers modify their behaviors or the environment to effectively deal with the situation, leading to an integrated coping process.

Though there are four modes of adaptation in Roy's model, this project focuses only on the interdependence mode of adaptation. This mode involves a person's relationships with others, and the giving and receiving of value, respect and love (Roy, 1976). Figure 2 illustrates the relationships between the Roy Adaptation Model, study components and measurements.

Conceptual Definitions of Terms

Alzheimer's disease is defined as a progressive type of dementia that destroys memory and other important mental functions (Alzheimer's Association, 2015). All care-recipients in this project have an Alzheimer's diagnosis confirmed by either their primary physician or neurologist as part of the screening process.

Caregiver/care-recipient dyads in this project face the challenge of adapting to changes in independence and dependence on each other (interdependence) due to an Alzheimer's disease diagnosis. This is particularly challenging when care-recipients start exhibiting BPSD, which can be confusing and even frightening to the caregiver (Kamiya, 2014). Failure to successfully adapt can lead to a compromised coping process, and consequentially, caregiver stress.

In this project, the Neuropsychiatric Inventory Questionnaire (NPI-Q) is used to measure caregiver stress and coping ability of the caregiver. The NPI-Q assesses caregiver stress level and coping ability related to 12 BPSD of the care-recipient (see Figure 4). Using a 0 to 5 Likert scale, a score of 0 is described as "not distressing at all", and a score of 5 is described as "extremely distressing, unable to cope with."

BPSD prevalence and severity are captured by the NPI-Q as well. Prevalence is determined by asking the caregiver about the presence of a care-recipient's BPSD. "Yes" scores one point, "No" scores zero points. If the caregiver answers yes, they are asked to describe the severity of the BPSD using a 1 to 3 discrete scale. A score of 1 is described as "mild", and a score of 3 is described as "severe."

Hypotheses

Key hypotheses explored are: 1) Care-recipients with higher scores in the mood subtypes contentment and spiritedness will correlate with lower caregiver stress, 2) care-recipients with

higher scores in the mood subtypes hostility, apathy and sadness will correlate with higher caregiver stress scores, 3) Care-recipients with higher scores of BPSD prevalence or BPSD severity will correlate with higher caregiver stress scores, and 4) Care-recipients with higher scores of BPSD prevalence or BPSD severity will correlate with higher mood subtype scores for hostility, apathy, and sadness, along with lower mood subtype scores for contentment and spiritedness.

Assumptions

This project assumes that the previous definitions and reports of caregiver stress by caregiver/care-recipient dyads with Alzheimer's disease will be applicable to the sample in this study. Another assumption is that the measures used to assess caregiver stress (NPI-Q) are valid and reliable instruments, and that participants will respond honestly and accurately. This project also assumes that each diagnosis of Alzheimer's disease as determined by physicians or neurologists is accurate.

Methods

Study Design

The parent study is a randomized controlled trial to test the effects of a 6-month moderate-intensity cycling program on cognition and hippocampal volume in older adults with Alzheimer's disease. The first participant was enrolled in June 2014. This thesis is a cross sectional, secondary data analysis of the parent study's baseline data. The project will use baseline data collected between June 2014 and September 2016.

Study Setting

The study was conducted in a large metropolitan area of the Midwest. The sampling method for the parent study is a convenience method. Participants either sought out the study

independently through online search engines, or were referred to the study by organizations such as the Alzheimer's Association, or referred by individual primary physicians or neurologists.

Study Sample

In order to be enrolled in the parent study, the participant must meet certain criteria.

Study inclusion criteria.

- Verified diagnosis of Alzheimer's disease
- Mini Mental State Exam score 15 to 26 out of 30
- Clinical Dementia Rating score 0.5 to 2
- Community dwelling
- Age 66 or older
- English-speaking
- Verified exercise safety
- If on Alzheimer's drugs, stable on drugs for one month or more.

Study exclusion criteria.

- Resting heart rate less than 50 bpm or greater than 100 bpm
- Neurologic disorders (non-Alzheimer's dementia, head trauma)
- Psychiatric disorders (bipolar, schizophrenia, major depression)
- Alcohol or chemical dependency
- Contraindications to exercise
- Abnormal MRI findings
- New symptoms or diseases that have not been evaluated by the primary care provider

- Abnormal findings from the symptom-limited cycle-ergometer test (cardiac ischemia, cardiac arrhythmia, inability to cycle)

Each participant must have a primary caregiver that knows the participant well enough to answer questions about the participant's mood, neuropsychiatric behaviors and activities of daily living.

In the event that the participant (care-recipient) scores lower than 80% on a study understanding quiz during the screening process, they sign an assent form and their caregiver signs the surrogate consent form.

Ethics

The parent study has been approved by the University of Minnesota IRB. All participants have given written consent or assent, or surrogate consent.

Measures/Variables

The following list contains the data domains collected during the baseline assessment.

Baseline data domains.

- Care-recipient mood
- Care-recipient BPSD prevalence
- Care-recipient BPSD severity
- Caregiver stress
- Ages of dyad
- Genders of dyad
- Race of dyad
- Educational status of dyad
- Relationship of dyad (spousal, parent-child, paid services)

Care-recipient mood subtypes are measured by the Alzheimer's Disease Mood Scale (AMS) (Figure 3). It is completed by the participant's caregiver. The instrument lists 34 words or short phrases to describe mood in the following subtypes: spirited, hostile, contented, apathetic, and sad. The caregiver rates the prevalence of each item on a 1 to 5 Likert scale, where 1 is "never" and 5 is "always." Key exceptions to this scale are for the items "cooperative" and "attentive", where 1 is "always" and 5 is "never." The Cronbach alpha values for the aforementioned mood subtypes are 0.92, 0.9, 0.85, 0.77 and 0.73 respectively (Tappen, 2009). The interrater reliability coefficient ranged from 0.88 to 0.63 (Tappen, 2009). These scores suggest that the AMS is a valid and reliable instrument to measure care-recipient moods.

BPSD prevalence, BPSD severity and caregiver stress are all measured by separate sections of the NPI-Q, also completed by the participant's caregiver (Figure 4). The instrument asks caregivers to affirm or deny BPSD of their care-recipients with a "yes" or "no." If "yes" is selected, the severity of the BPSD is recorded using a 1 to 3 discrete scale, with 1 as "mild" and 3 as "severe". The corresponding caregiver stress level is rated using a 0-5 scale, with 0 as "not distressing at all" and 5 as "extremely distressing, unable to cope with." The NPI-Q has been found to be valid and reliable, even in cross-cultural studies (Cummings, 2009).

Data collection

The cognitive tests pertinent to this thesis are administered in a consult room of the UMN's Clinical and Translational Science Institute. AMS and NPI-Q assessments are conducted by undergraduate research assistants or the project manager, who received training to administer those instruments. The AMS and NPI-Q data not collected in-person were collected over the telephone. This secondary analysis uses only the baseline data of the parent study to control for

any effect that the exercise treatments of the parent study may have on care-recipient mood, care-recipient BPSD, and caregiver stress.

Data analysis

Analysis was completed using SAS. Data analyses consisted of descriptive statistics, unadjusted analyses, and multivariate regression. Descriptive statistics were calculated for the outcome variable of caregiver baseline stress, the predictors of primary interest, and demographics. In addition, simple unadjusted correlations between the caregiver stress score and the primary predictors (care-recipient mood, BPSD prevalence and BPSD severity) and among the primary predictors were estimated.

Because many of the variables were integer-valued and non-normally distributed, Spearman's rank correlation was used. Sample correlations were tested against the null hypothesis of zero using the criterion of $p < .05$ for statistical significance. To assess the univariate relationship between caregiver and care-recipient demographics and the caregiver stress score, Spearman correlation was used for continuous variables (age) and ANOVA was used for categorical variables (gender, race, and education).

In order to further examine the relationship between the primary predictors and the caregiver's baseline stress score, a multivariate regression analysis was conducted. Because caregiver stress scores were non-negative and integer-valued, a generalized linear modeling approach was used. The care-recipient's mood subtype scores and BPSD scores were considered for inclusion in the model along with both the care-recipient's and caregiver's demographic variables. Variables with $p < .10$ were included in the final model, and the criterion of $p < .05$ was used for statistical significance.

Finally, a more thorough investigation of the relationship between care-recipient BPSD symptom measures (prevalence and severity) and care-recipient mood levels was conducted. A separate multivariate regression analysis was performed for each of the five mood variables to test, and estimate the magnitude of, the effect of the symptom prevalence and intensity variables on the respective mood scores, adjusting for possible confounding demographic variables. A generalized linear modeling approach was used with the same criterion for variable inclusion ($p < .10$) and statistical significance ($p < .05$) as described above

Results

The overall sample size for this project is 56 care-recipients and 56 caregivers. Participants who declined to answer demographic or stress-related questions were excluded from the secondary analysis (n=9, 16%). The final sample included 47 dyads.

Descriptive Statistics of Demographics and Baseline Data

Demographic variables and baseline questionnaire scores are summarized in Tables 1 and 2. The care-recipients were almost evenly split by sex (n= 26 and n=21 for males and females respectively). The average age of care-recipients was 78 years ± 6.4 years. The majority of caregivers were females (n= 38). The age of caregivers ranged from 32 to 87 years, with the average being 65 ± 14 years. Additionally, 45 out of 47 care-recipients and 45 out of 47 caregivers identified their ethnicity as white.

Relationship Between Care-recipient Mood and Caregiver Stress

Overall, the mood variables of contentment, hostility and sadness were significantly associated with caregiver stress in a univariate relationship (see Table 3). The correlations are as follows: Care-recipient contentment ($\rho = -0.43$, $p \leq 0.05$), hostility ($\rho = 0.35$, $p \leq 0.05$), sadness ($\rho =$

0.54, $p \leq 0.05$). Interestingly, after adjusting for gender, it was found that for each one-point increase in care-recipient contentment, caregiver stress increased by an average of 4%.

Relationship Between Care-recipient BPSD Prevalence, Severity and Caregiver Stress

Significant correlations were also found when examining caregiver stress scores against care-recipient BPSD prevalence and severity (see Table 4). Caregiver stress was strongly positively correlated with BPSD prevalence ($r = 0.78$, $p \leq 0.05$) and even more positively correlated with BPSD severity ($r = 0.84$, $p \leq 0.05$).)

Relationship Between Care-recipient BPSD Prevalence and Care-recipient Mood

It was found that BPSD prevalence was moderately associated with the care-recipient's hostility in a univariate relationship ($p < 0.0001$, $r = 0.54$). Care-recipients with a greater number of BPSD tended to have a higher score on the hostility scale. For a one-point increase in BPSD prevalence, the hostility score can be expected to increase by 9.5% (see Table 6).

Relationship Between Care-recipient BPSD Severity and Care-recipient Mood

BPSD severity and care-recipient sadness were weakly correlated ($p = 0.008$, $r = 0.48$). There was also evidence that BPSD severity was significantly related to the care-recipients' sadness scores ($p < 0.001$) after adjusting for care-recipient age. Care-recipients with higher BPSD severity tended to have higher sadness scores. For a one-point increase in BPSD severity, the care-recipient's sadness score can be expected to increase by around 8.5% (see Table 6).

The univariate relationship between BPSD severity and a care-recipient’s contentment was found to be significant ($p < 0.001$, $r = -0.58$). A higher BPSD severity score was associated with a lower level of care-recipient contentment. For each one-point increase in the severity, the contentment score of the care-recipient can be expected to decrease by approximately 3% (see Table 6).

Discussion

The overall results suggest that as the care-recipient scores higher in the mood subtype of sadness, hostility, BPSD prevalence or BPSD severity, the stress of the caregiver increases. The most significant mood variable was sadness, with a one point increase in care-recipient sadness predicting a 9.5% increase in caregiver stress. Furthermore, a one point increase in BPSD prevalence and severity predicts a 23% and 9% increase in caregiver stress respectively.

Using Spearman correlation coefficients, caregiver stress had a weak positive correlation with care-recipient hostility ($\rho = 0.35$, $p \leq 0.05$) and moderate positive correlation with care-recipient sadness ($\rho = 0.54$, $p \leq 0.05$). To corroborate, Izawa (2010) noted especially how the depressive symptoms of care-recipients correlated with depressive symptoms of caregivers, such as higher levels of stress. Additionally, caregiver stress had a moderate negative correlation with care-recipient contentment ($\rho = -0.43$, $p \leq 0.05$). This correlation aligns with McGilton's (2011) finding that the positive mood of residents in long-term care settings was associated with more effective caregiving abilities as demonstrated by the facility employees, though their study focused on paid employees, and this study focuses on family members acting as caregivers. However, contradictory to the negative univariate relationship found in Table 3, it was found that after adjusting for gender, a one-point increase in care-recipient contentment lead to a 4% increase in caregiver stress (see Table 5). Possible explanations for this result include the small sample size and the limitation of basing contentment off of one set of quantitative data. Perhaps if contentment was rated more widely through other measures, the caregiver stress relationship would prove negative in the regression analyses as expected. No significant values were found in examining caregiver stress against care-recipient apathy or spiritedness.

Additionally, some care-recipient mood subtypes were moderately correlated to each other. Care-recipient hostility and care-recipient contentment had a moderate negative correlation (-0.63). Care-recipient hostility and care-recipient sadness has a moderate positive correlation (0.44). Care-recipient sadness and care-recipient contentment has a moderate negative correlation (-0.43). Since all of the mood subtypes in the AMS data instrument are tallied separately and have no mathematic effect on the scores of other mood subtypes (it is possible for a care-recipient to score maximum points in all five subtypes), it seems that greater levels of hostile affect is tied to greater levels of sadness and lower levels of happiness. Kamiya (2014) states that verbal aggressiveness from the care-recipient is one of the largest stressors of caregivers, so perhaps if the care-recipient's depressive symptoms are treated, their hostile mood will decrease.

Regarding the relationship between BPSD prevalence and BPSD severity with caregiver stress, the results in Table 4 support previous research such as Kamiya's (2014) finding that as BPSD prevalence and severity increases, so does caregiver stress. Furthermore, the findings of this study support Matsumoto's (2007) finding that delusional thoughts, agitation, apathy, irritability or aberrant motor behaviors displayed by a loved one with Alzheimer's disease were related to higher levels of caregiver stress.

Moreover, BPSD prevalence was moderately correlated with the care-recipients hostility mood subtype scores. Since many of the BPSD listed on the NPI-Q such as irritability or aggression are hostile in nature, the correlation is reasonable. BPSD severity and care-recipient sadness scores were weakly correlated as well. The NPI-Q lists symptoms such as appetite changes, depression, and anxiety, all of which could manifest as sadness in the care-recipient. Finally, as expected, BPSD severity and care-recipient contentment were inversely related to

each other. However, causality is difficult to determine. It is uncertain if increased care-recipient happiness reduces the severity of BPSD, or if lower BPSD severity results in increased care-recipient happiness.

Within the context of Sister Callista Roy's Adaptation Model of Nursing, it would seem that caregivers caring for care-recipients with high hostility, sadness, BPSD prevalence and BPSD severity are likely in the Compromised Coping stage of adaptation to the Alzheimer's disease diagnosis, as evidenced by their higher-than-average stress scores. Unless the stressors are addressed with adequate coping mechanisms, the caregiver/care-recipient dyads will not be able to reach the Integrated Coping stage of adaptation. A suggestion for future research would be to assess baseline coping methods of the caregivers and their effectiveness in alleviating caregiving related stressors.

Limitations

Overall, the results of this study are valid and significant, but not generalizable to the general population. Potential limitations and weaknesses of the study are as follows: homogeneity in subject race, homogeneity in subject education, small sample size and lack of qualitative data. The homogeneity in race limits our understanding about how different races and cultures may experience stress and burden. Furthermore, since most of the participants in this study are college educated, it is plausible that they are financially stable enough as a result, and can afford to mitigate some of the burdens of caregiving through hired help, paid group activities and adult daycare centers not available to those of a lower socio-economic status. The small sample size makes it impractical to examine the relationships in subgroups, such as between gender and stress, or relationship type and stress.

It is also difficult to determine the isolated effects of care-recipient mood and BPSD on caregiver stress due to the intertwined nature of mood and behavioral symptoms. The caregiver of a sad care-recipient with high BPSD severity is likely stressed, but it is unclear if the stress is a result of the depressive symptoms of the care-recipient, or a result of the care-recipients high BPSD severity. Future research endeavors should examine whether care-recipient mood or BPSD affects caregiver stress levels more significantly.

Finally, during the data collection process, many caregivers offered impromptu stories about their caregiving experiences that augmented the story of the numbers collected from the quantitative instruments. These stories were never recorded nor analyzed in a qualitative manner. Therefore, the opportunity to collect, code, and analyze these stories for prominent themes was lost.

Conclusions and Recommendations

The results of this secondary analysis demonstrate that certain care-recipient moods are correlated with caregiver stress. Since the majority of research focuses on the effect of care-recipient functional ability and BPSD on stress, this study addresses a key gap in the literature and helps in furthering the dialogue of how moods and interpersonal dynamics affect caregiver stress. Nurses can apply certain findings of this study to their practice. For example, when screening a patient with Alzheimer's disease for depression, a high score could act as a potential flag for increased caregiver stress. Then, the nurse could attempt to start a dialogue with the dyad about stress, stress management and caregiver resources.

Future research that is augmented by qualitative mixed methods data and evaluates stress outcomes in a larger sample of caregivers caring for someone with Alzheimer's disease could lead to a more comprehensive understanding of caregiver stress. By adding qualitative input

from the caregivers and care-recipients to explain what quantitative data alone cannot, the nursing profession acts as a partner to those affected by Alzheimer's disease to create and utilize new interventions together.

Appendix

Figure 1: *Roy's Adaptation Model for Nursing*

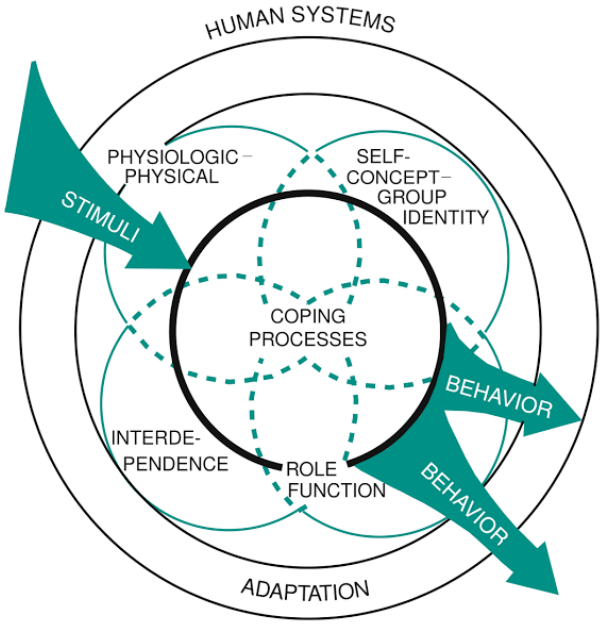
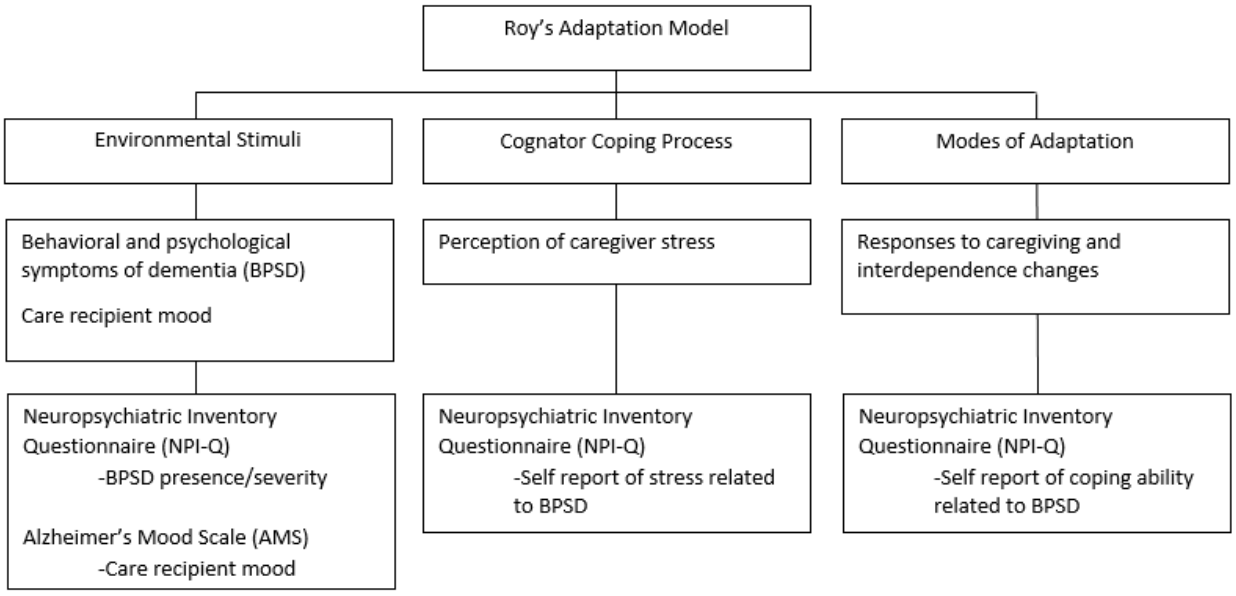


Figure 1

Figure 2: *Conceptual Definition of Terms*



Note. The top row represents certain components of Roy's Adaptation Model. The middle row represents specific study aspects as they relate to the components of Roy's Adaptation Model. Finally, the bottom row represents the measures used to examine the aforementioned components.

Figure 3: *Alzheimer's Disease Mood Scale*

Subject ID: _ _ _ Date:_ _/_ _/_ _ _ _ Time (military)_ _:_ _ Collector Name: (First)_____ (Last)_____

Alzheimer's Disease and Related Dementias MOOD SCALE (Revised)

Occasion (check one): ☐1 Baseline ☐2 Three Months ☐3 Six Months ☐4 Nine Months ☐5 Twelve Months

Instructions: Please think about the way the subject has been in the last seven days and indicate how often each word listed below would have described him or her over the last week.

	Never	Occasionally	Sometimes	Often	Always
Hostile					
1. In Bad Mood	1	2	3	4	5
2. Upset	1	2	3	4	5
3. Angry	1	2	3	4	5
4. Suspicious, Paranoid	1	2	3	4	5
5. Hateful	1	2	3	4	5
6. Irritated	1	2	3	4	5
7. Aggressive	1	2	3	4	5
8. Cooperative*	5	4	3	2	1
Apathetic					
9. Apathetic	1	2	3	4	5
10. Lost	1	2	3	4	5
11. Lack of Expression (Flat Affect)	1	2	3	4	5
12. Attentive*	5	4	3	2	1
13. Quiet	1	2	3	4	5
Sad					
14. Depressed	1	2	3	4	5
15. Sad	1	2	3	4	5
16. Tearful	1	2	3	4	5
17. Wants to Die	1	2	3	4	5
Contented					
18. Relaxed	1	2	3	4	5
19. Calm	1	2	3	4	5
20. Accepting	1	2	3	4	5
21. Feels Safe, Secure	1	2	3	4	5
22. Content	1	2	3	4	5
Spirited					
23. Wants Attention	1	2	3	4	5
24. Sense of Humor	1	2	3	4	5
25. Euphoric (very high spirits)	1	2	3	4	5
26. Wants Affection, Love	1	2	3	4	5
27. Likes to Do Things	1	2	3	4	5
28. Jovial	1	2	3	4	5
29. Affectionate	1	2	3	4	5
30. Likes to Be Busy	1	2	3	4	5
31. Enthusiastic	1	2	3	4	5
32. Talkative	1	2	3	4	5
33. In Good Spirits	1	2	3	4	5
34. Bright, Alert	1	2	3	4	5

AMS Subtotal Scores …….. Hostile (#1-8): _____ (8-40) Apathetic (#9-13): _____ (5-25)
Sad (#14-17): _____ (4-20) Contented (#18-22): _____ (5-25) Spirited (#23-34): _____ (12-60)

Page 1 of 1
The FIT-AD Trial

Figure 4: *Neuropsychiatric Inventory Questionnaire*

Subject ID: _ _ _ Date:_ _/_ _/_ _ _ _ Time (military)_ _:_ _ Collector Name: (First)_____(Last)_____

Neuropsychiatric Inventory Questionnaire - NPI-Q

Occasion (check one): ☐1 Baseline ☐2 Three Months ☐3 Six Months ☐4 Nine Months ☐5 Twelve Months

Circle "yes" or "no" in response to each question in the table:

- If the answer is "no," proceed to the next question.
- If the answer to a question is "yes," please:
  a) Rate the SEVERITY of the symptom (how it affects the subject):
  1 = Mild (noticeable, but not a significant change)
  2 = Moderate (significant, but not a dramatic change)
  3 = Severe (very marked or prominent, a dramatic change)

  b) Rate the DISTRESS you experience due to that symptom (how it affects you):
  0 = Not distressing at all
  1 = Minimal (slightly distressing, not a problem to cope with)
  2 = Mild (not very distressing, generally easy to cope with)
  3 = Moderate (Fairly distressing, not always easy to cope with)
  4 = Severe (very distressing, difficult to cope with)
  5 = Extreme or very severe (extremely distressing, unable to cope with)

Domain	Yes	No	Severity	Caregiver Distress
A. Delusions Does the subject have false beliefs, such as thinking that others are stealing from him/her or planning to harm him/her in some way?	☐	☐	1 2 3	0 1 2 3 4 5
B. Hallucinations Does the subject have hallucinations such as false visions or voices? Does he or she seem to hear or see things that are not present?	☐	☐	1 2 3	0 1 2 3 4 5
C. Agitation/Aggression Is the subject resistive to help from others at times, or hard to handle?	☐	☐	1 2 3	0 1 2 3 4 5
D. Depression/Dysphoria Does the subject seem sad or say that he/she is depressed?	☐	☐	1 2 3	0 1 2 3 4 5
E. Anxiety Does the subject become upset when separated from you? Does he/she have any other signs of nervousness such as shortness of breath, sighing being unable to relax, or feeling excessively tense?	☐	☐	1 2 3	0 1 2 3 4 5
F. Elation/Euphoria Does the subject appear to feel too good or act excessively happy?	☐	☐	1 2 3	0 1 2 3 4 5
G. Apathy/Indifference Does the subject seem less interested in his/her usual activities or in the activities and plans of others	☐	☐	1 2 3	0 1 2 3 4 5
H. Disinhibition Does the subject seem to act impulsively, for example, talking to strangers as if he/she knows them, or saying things that may hurt people's feelings?	☐	☐	1 2 3	0 1 2 3 4 5
I. Irritability/Liability Is the subject impatient and cranky? Does he/she have difficulty coping with delays or waiting for planned activities?	☐	☐	1 2 3	0 1 2 3 4 5
J. Aberrant Motor Behavior Does the subject engage in repetitive activities such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?	☐	☐	1 2 3	0 1 2 3 4 5
K. Sleep and Nighttime Behavior Disorders Does the subject awaken you during the night, rise too early in the morning, or take excessive naps during the day?	☐	☐	1 2 3	0 1 2 3 4 5
L. Appetite and Eating Disorders Has the subject lost or gained weight, or had a change in the type of food he/she likes?	☐	☐	1 2 3	0 1 2 3 4 5
Total score for severity and caregiver distress, respectively				

Page 1 of 1

Table 1

Subject demographics for caregivers (CG) and care-recipients (CR)

Variable	Mean	SD	Range
CR age in years	78.0	6.4	66-94
CR education in years	15.8	3.6	12-23
	n	%	
CR male	26	55.3	
CR female	21	44.7	
CR White	45	95.7	
CR non-White	2	4.3	
	Mean	SD	Range
CG age in years	65.1	14.0	32-87
CG education in years	16.2	2.1	12-20
	n	%	
CG male	9	19.1	
CG female	38	80.9	
CG White	45	95.7	
CG non-White	2	4.3	
	n	%	
Spousal dyad	30	63.8	
Parent-child dyad	14	29.8	
Other relationship	3	6.4	

Table 2

Baseline test scores with possible score ranges

Variable		Mean	SD	Min	Max
CG stress	*(0-60)*	7.36	5.73	0.0	20.0
BPSD prevalence	*(0-12)*	3.63	2.03	0.0	9.0
BPSD severity	*(0-36)*	5.59	3.92	0.0	16.0
CR hostile	*(0-32)*	5.39	3.78	0.0	32.0
CR apathy	*(0-20)*	6.52	3.51	0.0	14.0
CR sad	*(0-16)*	2.24	2.14	0.0	9.0
CR content	*(0-20)*	14.28	4.00	5.0	20.0
CR spirited	*(0-48)*	26.46	8.20	9.0	44.0

Note. The AMS ranges have been adjusted so that all minimums reach zero. The original AMS form does not allow for a score of zero in any category.

Table 3

Unadjusted correlations between caregiver (CG) stress and care-recipient (CR) mood types

	1	2	3	4	5	6
1. CG stress	---	**0.35***	**0.14**	**0.54***	**-0.43***	**-0.04**
2. CR hostile	---	---	0.31*	0.44*	-0.61*	-0.11
3. CR apathy	---	---	---	0.28*	-0.22	-0.37*
4. CR sad	---	---	---	---	-0.43*	-0.25
5. CR content	---	---	---	---	---	0.08
6. CR spirited	---	---	---	---	---	---

Note. Asterisk designates a significant value $p \leq 0.05$

Table 4

Correlations between caregiver (CG) stress, BPSD prevalence and BPSD severity

	1	2	3
1. CG stress	---	0.78*	0.84*
2. BPSD prevalence	---	---	0.92*
3. BPSD severity	---	---	---

Note. Asterisk designates a significant value $p \leq 0.05$

Table 5

Caregiver (CG) stress regression analysis of significant variables

Variable	SD of variable	Parameter Estimate	Expected change in stress per 1-point increase
CR content	4.0	1.04	4.3%
CR sad	2.1	1.09	9.5%
BPSD prevalence	2.0	1.21	23.0%
BPSD severity	3.9	1.08	9.0%

Table 6

Care-recipient (CR) BPSD and mood regression analysis of significant variables

	SD of variable	Parameter Estimate	Expected change in mood per 1-point increase
CR sad			
BPSD severity	3.9	1.08	8.5%
CR content			
BPSD severity	3.9	0.97	-3.1%
CR hostile			
BPSD prevalence	2.0	1.09	9.5%

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